

# Brain Injury Listening Sessions

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AUGUST 2017



Advisory Council on Brain Injuries

IOWA DEPT OF PUBLIC HEALTH

[HTTPS://IDPH.IOWA.GOV/BRAIN-INJURIES](https://idph.iowa.gov/brain-injuries)

## Introduction

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Brain Injury is a disruption in the normal function of the brain connected to a specific event. Typically referred to as either “acquired” or “traumatic,” a brain injury causes changes in a person’s thinking, emotions, behavior and language skills. Everybody is at risk for a brain injury; how the brain injury impacts an individual, however, will vary from person to person.

An external force to the head, such as a bump, blow, jolt, penetration or blast, causes traumatic brain injuries (TBI). Common causes of TBI are falls, car crashes, collision with an object or another person, and assaults. Concussions are a type of TBI.

Acquired brain injury (ABI) is the umbrella term used for all types of brain injury. ABI can be the result of a stroke, lack of oxygen to the brain, poisoning or overdose, or TBI.

Approximately 17,000 individuals are impacted by TBI in Iowa annually. This number does not include individuals that acquired a brain injury from stroke, infection, poisoning or other non-traumatic injuries, and it does not include the countless individuals who do not seek treatment for their brain injury.

The effects of brain injury create overwhelming challenges for the individual, as well as their family and others who are there to support them. The Governor’s Advisory Council on Brain Injuries’ mission is to represent individuals with brain injury, their families, and all Iowans through advocacy, education, training, rehabilitation, research and prevention. To accomplish its mission, the council regularly studies the needs of individuals with brain injury and their families; makes recommendations regarding the planning, development and administration of a comprehensive statewide delivery system; and promotes and implements injury prevention strategies.

Every four years, the council develops a state plan for brain injury as recommendations for the direction of service delivery and prevention efforts for the state. Listening sessions are one of the methods used to gather stakeholder input for developing the state plan.

## Methodology

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During the April 2017 meeting of the Advisory Council of Brain Injuries, council members made a request for listening sessions to be held across the state to gather stakeholder input into the next iteration of the state plan.

With assistance from the Brain Injury Alliance of Iowa (BIA-IA), six (6) sessions were planned and held during June and July. This included five in-person sessions which were held in Iowa City, Johnston, Sioux City, Mason City and Waterloo. These locations were selected due to their proximity to an office of the BIA-IA and the perceived stakeholder engagement in local brain injury issues or activities (e.g. brain injury services, support groups, advocacy). Additionally, one session was held using a web-based meeting platform so that individuals could participate remotely.

A flyer promoting the listening sessions was developed and disseminated via email to council members and the BIA-IA staff. Public notification of the sessions was conducted by sharing meeting information on the IDPH website and social media platforms. The BIA-IA also publicized the meetings through their social media platforms and targeted membership emails.

Using facilitated conversation, participants at each session discussed the following topics:

1. Barriers to accessing services,
2. Recommendations for service and supports development and enhancement,
3. Brain injury prevention strategies, and
4. Suggested populations for targeted outreach and support.

During each session, participants received information about neuro-resource facilitation and other programs of the BIA-IA.

### Summary of input

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Session participants included people with brain injury, family members, caregivers, professionals working for an organization supporting people with brain injury, and state legislators. Over the course of the listening sessions, similarities between the barriers and recommendations mentioned by participants emerged, which are listed below. Overarching themes consistently brought up across all sessions were lack of funding, need for increased awareness and training, and the limited availability or access to needed services and supports.

#### Barriers to accessing services and supports

- Lack of funding
- Financial and functional requirements prohibit people from accessing services/supports, particularly early on
- Lack of knowledgeable professionals such as doctors, educators
- Bottleneck of process to receiving services, including lengthy waiting lists
- Transportation (lack of funding and access, particularly for non-medical appointments)
- Uniqueness of brain injury between individuals
- Reduction in services or choice of service since the implementation of Medicaid Managed Care
- Lack of appropriate service options (post-acute rehabilitation and community-based residential facilities)
- Funding for services may stop if the individual doesn't demonstrate progress
- Lack of providers with brain injury expertise
- Regulations and limited funding prohibit participation in quality of life activities, like recreation and socialization

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#### Recommendations for services and supports development and enhancement

- Use of Mayo Portland Adaptability Inventory-4 as a brain injury assessment tool
- Increase activities promoting concussion awareness and management, including standardized information and resources across the state
- Improve access and availability of information; disseminate information in variety of ways
- Develop telehealth option
- Increase collaboration among similar groups for collective impact and uniform experience across the state
- Increase collaboration for continuity of care
- Increase information available on stroke and other types of non-traumatic brain injury
- Increase flexibility in use of funding (e.g., alternative medicine/healing; assistive technology)
- Re-calculate the waiver capitation rates
- Increase regionalized neuro-resource facilitation
- Develop more brain injury advocates across the state
- Develop ICF level of care for brain injury (similar to ICF-ID)
- Elevate qualifications and compensation for direct care professionals
- Make service coordination/case management available for people who are not on waiver
- Support or partner with existing programs to increase service availability throughout the state
- Increase awareness of neuro-resource facilitation and the BIA-IA
- Increase public awareness of brain injury (e.g., Iowa brain injury spokesperson/ambassador)
- Provide individuals and families with information about brain injury and resources earlier
- Provide advocacy and health literacy training to people with brain injury and their families
- Increased training targeting law enforcement, first responders, healthcare providers, mental health providers
- Provide education and training to families on crisis intervention and positive behavior support
- Increase collaboration between veteran and civilian systems
- Develop mechanism to fund access to alternative services (e.g., wellness opportunities, non-medical transportation, maintenance therapies)
- Provide more workforce development opportunities on brain injury topics

#### Brain injury prevention strategies

- Falls prevention
- All-terrain vehicle (ATV) safety, helmet use, licensing of youth
- Bicycle helmet distribution for youth and education (motorized riding toys, scooters, bikes)
- Prevention of secondary conditions/increased wellness opportunities
- Home safety education (falls, ladder safety)

#### Targeted populations for outreach and support

- Veterans
- Youth, particularly student athletes (concussion)
- Seniors
- Rural Iowans
- Homeless

- Individuals involved in the corrections or justice systems
- Survivors of abuse and violence
- Laborers (farmers, construction workers)
- People with multi-occurring conditions (e.g., mental health, substance abuse/addiction)

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Questions regarding the content of this report should be directed to the Iowa Department of Public Health's Brain Injury and Disability Program Manager, Maggie Ferguson, by emailing [brain.injury@idph.iowa.gov](mailto:brain.injury@idph.iowa.gov) or calling 515-281-8465.

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*For more information about the Iowa Dept. of Public Health's Brain Injury Services Program or the Iowa Advisory Council on Brain Injuries, please visit [www.idph.iowa.gov/brain-injuries](http://www.idph.iowa.gov/brain-injuries)*

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